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ABSTRACT

Research has shown that being a caregiver is often very stressful, particularly for individuals acting as caregivers for a demented elder. Caregivers might gain needed time to relax if there were leisure time activities available for demented individuals. A study was undertaken which involved development of the leisure activities; selection and pre-testing of caregivers and elders; use of activities and evaluation of their effect on caregivers; and follow-up of the effects once the activities were discontinued. Activity development resulted in 26 activities in the areas of games, arts and crafts, physical activities, and household activities. Participants were eight caregivers of demented male veterans who tried activities during weeks 3-8 of the 10-week participation period. Caregivers completed the Zarit Burden Scale before and after participation and recorded daily ratings of amount of relaxation experienced by the caregiver, time available for relaxation, and pleasantness of time spent interacting with their demented elder. Activity ratings were also obtained. The results of the pilot study revealed that elders spent an average of 33 minutes on a leisure activity each time they engaged in one. Caregivers, however, did not report more time to relax, nor did they report feeling more relaxed when their elders engaged in activities. In addition, caregivers did not perceive their interactions with their demented elders to be more pleasant on activity days. (NRB)

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LEISURE ACTIVITIES FOR DEMENTIA PATIENTS

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for the annual convention of the Western Gerontological Society, Denver, Colorado, March, 1985.

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Each year, an increasing number of individuals assume the role of caregiver for a frail elderly person (Shanas, 1979). Previous research has shown that being a caregiver is often very stressful, particularly for individuals acting as caregiver for a demented elder (Zarit, Reever & Bach-Peterson, 1980). A major source of caregiver stress is the lack of time available to the caregiver to relax and pursue his or her own interests. The demented elder may constantly demand the attention of their caregiver by asking the same question over and over again, following the caregiver around the house or simply needing to be "looked in on" at frequent intervals.

We felt that caregivers might gain much needed time to relax if there were leisure time activities available which demented individuals would find interesting and could safely pursue on their own (or with minimal supervision). Specifically, we predicted that:

1) leisure time activities for demented elders could be developed;
2) use of these leisure time activities by the demented elder would increase the amount of relaxation time available to the caregiver; and
3) use of these leisure time activities by the demented elder would increase the amount of relaxation experienced by the caregiver.

In addition, leisure time activities which allow the participation of both the caregiver and the demented elder might enhance the pleasantness of their interactions by providing an alternative to the repetitive questions and demands frequently made by demented individuals.

We therefore designed a pilot study to determine if appropriate lesiure time activities for demented elders could be developed and to gather preliminary evidence about the previously mentioned predictions concerning the effects of such activities on caregivers. The study consisted of four components: development of the leisure activities; selection and pre-testing of the participating caregivers and their elders; use of the activities and the systematic evaluation of their effect on the caregiver; and a follow-up of the effects once the activities were discontinued. I will describe each of the components.

Method

Development of the Activities

Considerable time was devoted to the development of the leisure time activities by a team composed of social workers, an occupational therapist and a psychologist. Details of this development will be presented at this conference in a lecture entitled Leisure Activities for the Demented: Developing a Family Self-help Module. Briefly, the team developed an initial list of activities on the basis of their experience with demented elders and their caregivers and a survey of activities offered in local adult day care programs. Under the guidance of the occupational therapist, the team subjected each of the initial activities to an "activity analysis" to determine what perceptual, cognitive and motor skills they required. Activities judged to be too difficult were discarded. The final list contained 26 activities of four different types:

games: such as dominoes, lotto, simple memory games, etc.

arts & crafts: such as a leather kit, a wooden cutting board needing sanded and oiled, doodle art, etc.

physical activities: such as nerf ball games, singing/dancing, massage, etc.

household activities: such as sweeping, setting the table, dusting, etc.

Instructions were written for each of the activities. Many of the common games such as dominoes were given much more simple instructions than those typically used. Also, some of the activities required the participation of two people, e.g. massage, dancing.

Selecting Participants

Participants in the study were volunteers recruited from the case load of the Hospital Based Home Care Program. Eight caregivers of demented male venterans agreed to try the activities and complete the daily evaluation measures over a 10 week period.

The demented elders had a mean score of 18.5 on the Mini Mental Status Exam, indicating substantial impairment of cognitive functioning. The Caregivers had a mean score of 37.2 on the Zarit Burden Scale, indicating the presence of significant levels of caregiver burden.

Measures Used

In addition to the Zarit Burden Scale, caregivers completed several self-report ratings. Daily ratings were obtained for:

amount of relaxation experienced by the caregiver

(1-no relaxation to 3-extremely relaxed)

time available to the caregiver for relaxation

(1-no time to 3-all the time I wanted)

pleasantness of time spent interacting withdemented elder

(1-not pleasant to 3-extremely pleasant)

Each day, caregivers were also asked to indicate which, if any, of the following four services they had utilized: sitters for their elder, daycare/day health programs, in-home medical care; or inpatient respite care. This information was collected so that we could determine if the caregivers ratings on the previously mentioned variables were being influenced by their use of methods other than the leisure activities to obtain time for themselves. Caregivers also indicated whether their demented elder had engaged in any activities in each of the following categories: games, arts and crafts, physical activities, or household chores/activities. This general question about activities was asked to provide us with a rough index of activities other than those used in the study in which the demented elder might be engaging.

Activity ratings were obtained each time the caregiver attempted to have their demented elder participate in one of the leisure activities developed for the study. These ratings included:

the number of minutes the demented elder spent on the leisure activity

the amount of time the caregiver spent on the leisure activity

(1-almost no time to 5-as much or more time as my elder)

how enjoyable the demented elder seemed to find the activity

(1-not at all enjoyable to 5-extremely enjoyable)

how relaxing the time spent on the activity by the demented elder was for the caregiver

(1-not at all enjoyable to 5-extremely enjoyable)

Procedures

After completing the Zarit Burden Scale, each participating caregiver was asked to complete the five daily ratings at the end of each day for the next two weeks. The leisure activities were introduced during week 3. Each caregiver was given instructions and materials for 4 different activities (one from each of the four types of activities). The caregiver was asked to select one of the 4 activities and make it available to their demented elder on at least three different days of the week. Each week for the next 6 weeks, the caregivers were given new sets of activities. The order in which the activities were presented was randomized across subjects. Caregivers were asked to complete the four activity ratings immediately after their demented elder had engaged in one of the study's leisure activities. During the intervention period (i.e. weeks 3 thru 8), caregivers were also asked to complete the daily ratings at the end of each day. Once each week, each participant was called by the project coordinator to see if the participant was experiencing any problems with the activities or the self-report forms. Nine weeks after the beginning of the study, the caregivers were not presented with any additional activities but were asked to keep recording their daily ratings for the next two weeks. They were encouraged to use any of the leisure activities made available during the previous 8 weeks. At the end of the study, each caregiver again completed the Zarit Burden Scale.

Results

The results of the pilot study can best be summarized by reviewing the questions we set out to answer.

Did the demented elders spend time engaging in the leisure activities we developed?
Yes, the elders spent an average of 33 minutes on a leisure activity each time they engaged in one. However, only a few of the activities contributed significantly to this average. Dot-to-dot drawings, and dominoes were frequently chosen activities and elders spent an average of 34 minutes on both. The leather craft project was also popular. Elders averaged 18 minutes of activity each time they engaged in leather craft.

Did the caregivers report more time to relax on days during which their elders engaged in the leisure activities?
No, the average rating of time available for relaxation was 2.6 on activity days and 2.5 on nonactivity days. The difference is not statistically significant and indicates that the caregivers rated themselves as having somewhere between "very little time to relax" and "a moderate amount of time to relax".

Did the caregivers report feeling more relaxed on days during which their demented elder engaged in leisure activities?
No, the average relaxation rating was 2.5 for both activity days and nonactivity days. The average rating fell between the "slightly relaxed" and "moderately relaxed" category.

Did the caregivers perceive their interactions with their demented elder to be more pleasant on the days in which their demented elder engaged in leisure activities?
No, the average rating of the pleasantness of interactions was 2.7 for both activity days and nonactivity days. The average rating was slightly below the category "moderately pleasant interactions".

The failure of the data to support our original predictions led us to inspect the other ratings provided by the caregivers for suggestions about why the leisure activities did not have their expected positive effect on the caregivers. Several potential reasons emerged. The elders did not tend to spend long amounts of time on the activities. Thirty

minutes (the average time spent) would not necessarily feel like a meaningful increase in free time to a stressed caregiver. In addition, caregivers reported having to spend some time (mean rating=2.3) helping their demented elder on almost all the activities. This further reduced the free time we hoped the activities would generate for the caregivers. Lastly, the caregivers rated the time spent by their demented elder on the activities as somewhat less than "moderately relaxing" for themselves (mean rating=2.7).

We wondered what factors were associated with day to day changes in the amount of relaxation experienced by the caregivers since the elders' participation in our leisure activities had relatively little impact. There was a moderate, positive correlation ($r=.30$, $p<.01$) between the number of activity categories checked each day (i.e. the rough index of the total amount of activity engaged in by the elder) and the caregivers' daily ratings of relaxation. This suggests that there is a moderate tendency for caregivers to feel more relaxed on days in which their demented elder is more active. A much stronger association was observed between daily ratings of relaxation and the rated pleasantness of caregiver-elder interactions ($r=.60$, $p<.0001$). It appears that the days during which the social interactions between caregivers and their elders is most pleasant tend to be the days which caregivers report to be the most relaxing.

Conclusions

In general, the results of this pilot study do not support the notion that providing leisure time activities for demented elders will necessarily provide their caregivers with more time to relax, greater feelings of relaxation or increased pleasantness in their interactions with their elder. Several possible reasons for this lack of effect need to be explored. The leisure activities used may have been too difficult for demented elders to engage in without specific training. We did not attempt to assess how clearly the caregivers presented the activities to their elders or how persistent they were in the face of initial disinterest. The activities may also have been inherently (and permanently) uninteresting to the elders. We used children's toys and games as the basis for many of our activities and they contained pictures and other features which would not be familiar to most older adults. It is encouraging, however, that three of the 26 activities were generally popular: dot-to-dot drawings, leather craft and dominoes. Further study of these three activities might help reveal what characteristics an activity needs in order to

appeal to demented elders.

We were encouraged by the finding that caregivers' feelings of relaxation may be greater when their elders are generally more active (as indicated by the number of activity categories checked daily). Although our leisure activities did not appear to affect the elder's activity level substantially, a more appropriate set of activities could have such an effect, thereby enhancing caregiver relaxation as we had initially predicted.

The most interesting finding was the strong positive relationship between caregivers' relaxation ratings and their ratings of the pleasantness of their social interactions with their elder. This finding suggests that it may actually be more important to develop activities which allow the caregiver and their demented elder to interact in a pleasant way than to develop activities which do not require the presence of the caregiver.

There is clearly much more work that needs to be done in the field of leisure research for demented elders. We hope the results of this pilot study and the questions it has raised will encourage further investigations.

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